

# SWALLOW TALES

The Newsletter of the Esophageal Cancer Awareness Association, Inc.



PO Box 55017#15530, Boston, MA 02205-5071  
www.ecaware.org

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## President's Message

By Lois Dickerman PhD

As I write this message for the January issue of Swallow Tales, it is still in December and the New Year is not yet upon us. The thoughts that I have as I reflect in this holiday season are joyous and thankful ones that my husband and I have been so blessed this year and wistful ones that others are still struggling with esophageal cancer.



And then there are the sorrowful thoughts that friends and acquaintances we have met either in person or through correspondence are no longer with us. How I wish that I could personally comfort all of the loved ones who are facing this New Year still in sorrow and pain from loss. To those of you in this situation, I wish you the comfort of your indelible memories, as well as love,

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## New ECAA Merchandise

Your association has commissioned a new enamel ECAA Pin.

Now you can wear your association with the ECAA on any occasion; informal – on your fishing, hiking, or jogging cap, on your sweater; or formal – as a tie tack or lapel pin.

The pin is sure to attract attention and questions, helping you to raise awareness of esophageal cancer and the dangers of GERD person by person.

The pin is just \$3.00 and all proceeds go towards our aims of raising the awareness of esophageal cancer among the public. Go to [www.ecaware.org](http://www.ecaware.org) to order.



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*President's Message – from page 1*

happiness, families, and friends to fill your lives now. May the New Year take you down a path lighted with wonderful memories!

The New Year, of course, is a time to plan for the future and to set a new course, if needed. We have seen an amazing rise in the number of members of ECAA this year, as you readers responded to our call to join. We are in the process of compiling our lists of contacts by state, so that we can let each of you know of other Esophageal Cancer families in your areas. One of the most difficult problems in dealing with EC is the feeling of being alone and isolated. There are few EC patients and families to meet at most cancer centers and no means to know that others are feeling the same sense of isolation and bewilderment that you are feeling, whether patient or loved one. It is the avowed promise of the Board that we will try our best, region by region and state by state, to end this isolation. It may take months before we can collect EC contacts in every state, but we promise you that we are trying and will continue to make progress.

We also promise to continue with our issues of Swallow Tales, but we also plead for you readers to write to us to let us know what you would like to see in future issues. Please send us your suggestions and ideas. More importantly, we want you to share your experiences, your thoughts, your ideas and your stories, whether typical, funny, sad or educational. Swallow Tales is written for you the readers, but in 2009, we want to see more written BY you. We want you to make Swallow Tales truly yours. –E–

## ECAA Board Positions Open

Many people, when first confronted with this disease, are surprised and often angry that there is little information about EC in the public eye. They struggle to find information. They need to talk face to face with people who have walked in their shoes. They cry out “Why isn’t more done?”

Well, now is your opportunity to get involved and make a difference in people’s lives.

The ECAA is looking for volunteer members to join the board. The role of board member is a voluntary unpaid position, and the main contribution that any board member can bring to the association is the commitment and drive to help us fulfill our aim of increasing the awareness of this dire disease.

We are particularly interested in filling the position of Membership Coordinator. The task of the membership coordinator is to establish a committee of members that can:

- Promote membership in the society.
- Help to organize state, regional, and city groups for local support, outreach, fundraising, and publicity of our cause.

This role is demanding. It requires personal drive and time commitment. You must be competent with electronic communications and with record-keeping using computer spreadsheet and word processor software. The ability to relate to patients, survivors, care-givers, and loved ones is of course crucial.

If you have been wondering what you can do to fight this disease, now is your opportunity.

Please respond to Lois Dickerman at P.O. Box 55071 #15530, Boston MA 02205-5071.

## Farewell to the Belfast Cowboy

A Tribute to the Courage, Humor, and Personality of Ray Warke

*By Roger Tunsley*



**Ray Warke - The Belfast Cowboy**

Ray Warke was diagnosed with esophageal cancer in April of 2005, and began treatment that year culminating in a minimally invasive esophagectomy in June 2005. The cancer reappeared in July 2006, and Ray and his wife Rachael fought it together until he succumbed to the disease on November 10<sup>th</sup>, 2008.

*Ray Warke – from page 3*

This in itself is a sad but unremarkable story to many of the readers of this newsletter. But many of us know Ray as a remarkable person. He began to document his fight with cancer on his web site [www.raywarke.com](http://www.raywarke.com), but more importantly he began to read, and correspond with, the ACOR EC-Group list. The EC-Group is a place where EC patients, survivors, caregivers, and loved ones can share their feelings, give and seek advice, rant, joke, and support one another.

The EC-Group has many outstanding characters. Ray was one of these. An unfailing good humor typified his postings to the site. His love for his wife Rachael shone through his writing. But most of all, he was a source of sheer inspiration to us all.

Ray was a performer and songwriter. Soon after his cancer reappeared in 2006, and while undergoing concurrent chemotherapy and radiotherapy, he began to write songs about his experiences. He published these on his web site and eventually made a CD of his recordings and began to sell them from his site. All the income from these sales went in support of esophageal cancer support groups in the UK where he lived.

Like many who read the EC-Group mailings, I followed Ray's story and even though it was plainly near, I was dreadfully saddened to read of Ray's death. But when you think of the support he offered to everyone on the group, it is not possible to do anything other than smile.

I have included as a tribute, with Rachael's permission, the lyrics of some of the songs that he (re)wrote.

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## Stayin' Alive

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*To the tune of Stayin' Alive by the Bee Gees.*

Well, you can tell by the way I wear my pump,  
I'm a chemo man: gonna get that lump!  
Top and bottom, left and right,  
Gonna kick it around, I got odds to fight!

But it's all right, It's OK,  
The ulcers all will go away.  
Got burnin' feet inside my shoes,  
but I'm a chemo man and I just can't lose.

Whether it's cisplatin, or maybe carboplatin,  
you're stayin' alive, stayin' alive!  
your brain's a ball of cotton and your body's feelin'  
rotten,  
but you're stayin' alive, stayin' alive!

Ah, ha, ha, ha, stayin' alive, stayin' alive.  
Ah, ha, ha, ha, stayin' alive!

You can tell by the way I'm movin' quick,  
I'm in a hurry man, I'm gonna be sick!  
Feeling hot, feelin' numb,  
too tired to walk, but I got the runs!

But it's all right, It's OK!  
I'll learn to pee another way,  
Sat on the john, cause I can't stand,  
It's a whole new stance for chemo man!

Whether it's cisplatin, or maybe carboplatin,  
you're stayin' alive, stayin' alive!  
your brain's a ball of cotton and your body's feelin' rotten,  
but you're stayin' alive, stayin' alive!

You can tell by the way I wear my hair,  
I'm a chemo man, and I've got none there!  
But being bald is all the rage,  
at the cancer club, no matter what the age!

And it's alright, it's OK,  
I'll wear my hair another way!  
with a duster and a polish can,  
it's a whole new look for chemo man!

Whether it's cisplatin, or maybe carboplatin,  
you're stayin' alive, stayin' alive!  
your brain's a ball of cotton and your body's feelin' rotten,  
but you're stayin' alive, stayin' alive!

Ah, ha, ha, ha, stayin' alive, stayin' alive,  
Ah, ha, ha, ha, stayin' alive!

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*See Ray Warke on page 5*

*Ray Warke – from page 4*

## The Twelve Days Of Treatment

*A slight variation on the traditional tune*

On the first day of treatment,  
My doctor used a scope,  
That's a camera on the end of a piece of rope!

On my second day of treatment,  
He used an ultrasound,  
And he told me exactly what he found!

On the third day of treatment,  
I lay down for a scan,  
And I wondered if I would get a tan!

On the fourth day of treatment,  
He used a scanner called a PET,  
Something told me he wasn't finished yet!

On the fifth day of treatment,  
He said there was a lump,  
So they issued me with a 5FU pump!

On the sixth day of treatment,  
I was sat upon the loo,  
And the mouth sores were pretty nasty too!

On the seventh day of treatment,  
The lump began to shrink,  
And guess what? I could eat and drink!

On the eighth day of treatment,  
I thought the doc was nuts,  
When he told me he'd take away my guts!

On the ninth day of treatment,  
He put me off to sleep,  
In a room where machines would all go beep!

On the tenth day of treatment,  
I couldn't eat a thing,  
And this verse is the hardest verse to sing!

On the eleventh day of treatment,  
My wounds began to heal,  
And at last, I could eat a proper meal!

On the twelfth day of treatment,  
My doctor said to me,  
"Go home Ray, I think you're cancer free!"

## Nights on Cisplatin

*To the tune of Nights in White Satin by the Moody Blues*

Nights on cisplatin,  
Never reaching the end.  
Sweatin' and shiverin'  
With aches in my head.

Sick in my belly  
Numb fingers and toes,  
A dry mouth with ulcers  
A wet runny nose.

But I'm fightin'!  
Yes, I'm fightin'!  
Oh how I'm fightin'!

Tinnitus ringing,  
Sounds in the air,  
Losing my hearing  
As fast as my hair.

Thinkin' of people  
Who have played the same hand .  
Just what I'm goin' through  
They can understand .

'Cause we're fightin'!  
Yes, we're fightin'!  
Oh, how we're fightin'!

Nights on cisplatin,  
Never reaching the end.  
Sleepless and dreamless  
Hours to spend.

Slumber is always missed  
Like all nights before.  
Is this what the cure is?  
I can't tell anymore!

But I'm fightin'!  
Yes, I'm fightin'!  
Oh, how I'm fightin'!

Yes, we're fightin'!  
We're all fightin'!  
Oh, how we're fightin'!

*Ray Warke – from page 5*

And finally, a tale from Ray's site, author unknown.

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## Diet? What Diet?

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In the beginning God covered the earth with broccoli, cauliflower and spinach, with green, yellow and red vegetables of all kinds so Man and Woman would live long and healthy lives.

Then using God's bountiful gifts, Satan created Dairy Ice Cream and Eskimo Pies. And Satan said "You want hot fudge with that? And Man said "Yes!" And Woman said "I'll have one too with chocolate chips". And lo they gained 10 pounds.

And God created the healthy yoghurt that woman might keep the figure that man found so fair.

And Satan brought forth white flour from the wheat and sugar from the cane and combined them. And Woman went from size 12 to size 14.

So God said "Try my fresh green salad". And Satan presented Blue Cheese dressing and garlic croutons on the side. And Man and Woman unfastened their belts following the repast.

God then said "I have sent you healthy vegetables and olive oil in which to cook them". And Satan brought forth deep fried coconut king prawns, butter-dipped lobster chunks and chicken fried steak, so big it needed its own platter and Man's cholesterol went through the roof.

Then God brought forth the potato, naturally low in fat and brimming with potassium and good nutrition.

Then Satan peeled off the healthy skin and sliced the starchy centre into chips and deep fried them in animal fats adding copious quantities of salt. And Man put on more pounds. God then brought forth running shoes so that his Children might lose those extra pounds.

And Satan came forth with a cable TV with remote control so Man would not have to toil changing the channels. And Man and Woman laughed and cried before the flickering light and started wearing stretch jogging suits.

Then God gave lean beef so that Man might consume fewer calories and still satisfy his appetite.

And Satan created McDonalds and the 99cent double cheeseburger. Then Satan said "You want fries with that?" And Man replied "Yes, And super size 'em". And Satan said "It is good." And Man and Woman developed esophageal cancer.

God sighed ..... and created the trans-hiatal esophagectomy and the minimally invasive technique too.

And then ..... Satan chuckled and created HMOs and the National Health Service!

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Farewell Ray – thanks for your help. -£-

## Don't Ignore Chronic Heartburn

*By Heather Maloney, Beth Israel Deaconess Medical Center Staff, Boston*

Many people are plagued by pesky heartburn, especially after indulging in a spicy meal. But in some cases, what you think is just a late-night irritation may be something more serious.

Barrett's esophagus is a disorder in which the lining of the esophagus (the tube that carries food from the throat to the stomach) is damaged. The damage is caused by stomach acid that leaks back into the esophagus, commonly known as heartburn. Barrett's esophagus itself does not cause symptoms, but the acid reflux that causes the condition results in symptoms of heartburn. In some cases, Barrett's esophagus can progress to cancer of the esophagus.

According to Dr. Douglas Pleskow, Co-Director of GI Endoscopy at Beth Israel Deaconess Medical Center in Boston, if you suffer from Barrett's esophagus, your risk for developing esophageal cancer is about 15 times higher than the general population.

"The rate of esophageal cancer is six times what it was in the 1970s, though we don't know why," Dr. Pleskow says. "White males with longstanding heartburn are at greatest risk."

The severity of this form of cancer requires early diagnosis and treatment. "We really want to diagnose this before people start having symptoms," Dr. Pleskow says. "If we wait, esophageal cancer advances very quickly. The cure rate for this type of cancer is quite dismal."

The good news is that there's a new treatment for Barrett's esophagus, called radiofrequency ablation, which has proven to be very effective for many patients. BIDMC was the first in New England to offer this therapy for Barrett's esophagus.

"The cure rate using radiofrequency ablation is 80 percent," Dr. Pleskow says. "Until now, Barrett's was not curable by standard techniques. I think this is one of most exciting advances in GI endoscopy in five years," he says. "Before, we really didn't have any therapy for this. We used to have to do surgery, but now we have an alternative."

During radiofrequency ablation, the physician uses an endoscope with a balloon catheter at its tip to destroy a thin layer of surface tissue that contains the problem cells. This allows normal tissue to grow back in the esophagus. After approximately two months, doctors can check the site and, if abnormal cells remain, can go back and repeat the procedure.

Dr. Pleskow points out that radiofrequency ablation carries very little risk and has few side effects. Some patients experience minor pain following the procedure, which is typically treated with Tylenol or an antacid. "This procedure doesn't replace surgery for everyone," he says. "But for many people, it's a good option."

So how do you know if your recurrent heartburn is something more serious? "If you have daily heartburn symptoms, or your symptoms are not well controlled with your current regimen of medications, you may be at risk," he says.

Similarly, if you suffer from the following symptoms, it could be more than just heartburn and you should contact your doctor:

- weight loss
- difficulty swallowing
- vomiting blood or black/brown fluid
- passing blood or black, tarry stools
- wheezing at night

## Ten Years After

*By Steve Preston*

No this isn't a story about the infamous Woodstock band "Ten Years After". Some of you are going "HUH"? While others are thinking..."OH YEAH I REMEMBER THEM"! Those are the people who inhaled [a Clinton joke]!!! I'll try to get serious for a moment.

For those of you who don't know me...I was actually diagnosed in February 1997 with stage 2/3 esophageal/stomach cancer. I had the Ivor Lewis surgery that same month. Unlike most of you the medical "practice" wasn't as accommodating to patients researching or, better yet, getting educated on their disease on something as ridiculous as the internet. It was taboo and an insult to them.

I had no pre-op chemo or radiation because of the concern of advancement of the disease. And no post-op chemo or radiation because margins were clean and the chemo would have killed me due to excessive weight loss already occurring. In addition to dealing with cancer I also had to deal with bacterial spinal meningitis, staph and strep infections, two brain abscesses [one had ruptured] and complications from a wood splitting accident.

Why am I here today? I don't know. But I do know that God's mercy didn't hurt. I have been blessed to say the least. What caused the cancer is not a discussion for now. What has happened in the past ten years is. In the past ten years I've been blessed to meet many people who have had their lives changed by this disease. Some have become friends and sadly some have not won their battle. A couple were brother firefighters who were friends of mine before being diagnosed.

As you all know, it is a challenge getting through all of the tests, treatments and surgical issues. And then there are the dietary changes, depression issues, financial issues and the unexpected family issues. One thing I have learned in ten years from all of you is that anything is possible. Whether it's as dreadful as having a spouse walk away under the stress or losing everything you own during a hurricane and then losing the "battle w/the beast". But on a happy note are the miracle stories. The archives are LOADED with real life stories of those who were told to "get your things in order" or "there is no hope" and they took action and are here, today, to talk about it! If there is anything that folks get out of this "sermon"...it's DON'T GIVE UP. If a doctor tells you there is "no hope" get more opinions. What do you have to lose? If your chemo isn't working....try...even beg for another chemo recipe. Or seek new approaches as the Dickermans did. Knowing firsthand what an incorrect diagnosis can do, as I have several years post-op., it's a wake-up call that the medical field can be wrong. Listening to them is important but keep in mind the possibility that there may be other alternatives.

This was supposed to be about "Ten Years After". And it is. Twelve years ago, I would never have thought I would be here today. I would never have believed the education I've received over the past 12 years. How is life for me today? I'm NED but I still have my moments. I continue to work as a firefighter and volunteer my time off as a firefighter in the town that I live. I've learned to live w/the occasional dumping or hypoglycemia events. Sometimes it's even humiliating. But you also need to have a sense of humor. It beats the alternative. Eating has become an art...even today. Tachycardia [very rapid heartbeat] is common after many meals. Sleeping habits have changed as well. Reflux at night happens from time to time.

Above all, I'm fortunate to be here. I am blessed to be with such a caring, diverse and extended family in the cancer world. None of us will ever forget that moment of being diagnosed. I continue to have semi-annual endoscopies' due to excessive stomach acid production. I take 160 mg of Nexium a day. And many days can be challenging. And losing friends/relatives that we've met in this group can take a mental toll. But the level of support, treatment options, awareness and most importantly....becoming a survivor with a good quality of life has increased over the past ten years. Some day cancer will be a disease of the past. But until then live one day at a time and as Crosby, Stills and Nash wrote [in a song] LOVE THE ONE YOU'RE WITH! May God bless all of you, no matter where you are in this dreadful disease. -E-

## It Takes an E-Village

*By Ruth White*

Since I was diagnosed with esophageal cancer in 2006, my road to recovery has been quick; a trial and error adventure.

My treatment, consisting of chemo and surgery, was successful but the path to recuperation is like exploring uncharted territories. My doctors told me that the surgery would be a life altering experience, unlike any of the other surgeries that I have ever had previously for the other cancers that I had had and they were right. As far as what to expect after surgery and how to react during this life altering process, it can be a very frustrating and lonely road. Other cancers out there like breast and lung cancer have been well researched, which is a good thing, but EC doesn't have much research, therefore the doctors don't have a lot of answers as to what to expect.

Don't get me wrong, I am grateful as hell to be alive, but my point is that it takes an-e village to get through this very painful disease. If it wasn't for the support of my husband, family and close friends, I know that I would not have made it. I am very fortunate to have them, but I wanted to make it very clear that one resource I have found to be invaluable is that of my on-line friends.

Joining the EC on-line support group was one of the best things that I could have done to help me gain knowledge and answers to some of my unique questions. You think you are alone and that something is wrong with you when the doctors cannot answer your questions, but with this group I learned that others out there have had the same symptoms and problems that I have and I have been able to share my experiences with them and have learned what has worked and not worked for them. When faced with a problem, I have been able to share with this group and have received very helpful suggestions. What better advice can one get, than that from others who have been there and are going through the same thing? The doctors have only so many suggestions; they really don't know firsthand what works and what doesn't.

Living with EC is definitely a trial and error journey and it takes an e-village to get through it. Really no matter what type of disease of affliction that one has, one of the best resources available out there, in my opinion, is an e-group. E-groups are a wealth of valuable knowledge and information from caring human beings who have been there, and it is free. -E-

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To join the ACOR EC-Group mailing list, send mail to  
[LISTSERV@LISTSERV.ACOR.ORG](mailto:LISTSERV@LISTSERV.ACOR.ORG)  
with the command  
**SUBSCRIBE EC-GROUP**  
in the Subject line.

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## What Can You Do To Help?

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The ECAA is a small organization and depends upon membership, donations and merchandise sales for all income.

We have no paid staff; we are an all-volunteer organization.

So what can you do?

- Join us - only \$25 for life membership.
- Purchase our pins, shirts, caps, and wristbands to help raise the awareness of this disease in our community.
- Donate in memory of someone, or in support of someone in treatment.
- Volunteer your time and energy to help us increase membership, form member groups, pass out information on EC, reach out to patients and caregivers..

You can be sure that every penny donated goes toward raising the awareness of esophageal cancer in the general public and the medical profession.

Help somebody. Donate to the ECAA.

Go to [www.ecaware.org](http://www.ecaware.org)

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**Important note: Articles published in this newsletter are from many sources and cover a wide range of topics. They are published for the benefit of our readers, but they do not necessarily represent the views of the Esophageal Cancer Awareness Association.**

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# Membership Form

Thank you for your interest in membership of the Esophageal Cancer Awareness Association.

The ECAA depends on its active members to ensure our growth and to increase our ability to spread awareness of esophageal cancer to the general public and to the medical community.

ECAA life membership is \$25.00 for a single membership or \$30.00 for a couple (husband and wife, partnerships, patient and caregiver, and so on). This is tax-deductible.

Please send your details and a check for your membership to:

Dick Dickerman (ECAA Treasurer), P.O. Box 55071 #15530, Boston MA 02205-5071

## Personal Details

Name (Last, First): \_\_\_\_\_

Address: \_\_\_\_\_

Phone : \_\_\_\_\_(H) \_\_\_\_\_(M)

Email: \_\_\_\_\_

## Interest (Optional)

- I am an esophageal cancer patient or survivor
- I am or was a caregiver to an esophageal cancer patient or survivor
- I am a medical professional
- Other (Please specify) \_\_\_\_\_

## Volunteer Interest

- Form a local support or contact group
- Outreach to patients
- Distribute support materials at clinics and hospitals
- Membership campaigns
- Fundraising